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ABSTRACT

The paper describes approaches and findings of an evaluation of 10 advocacy projects providing services to developmentally disabled and mentally ill persons across the country. The projects included internal rights protection organizations, independent legal advocacy mechanisms, self-advocacy training centers, and legal advocacy providers in conjunction with local government. The evaluation process included four instruments used to collect information: individual client profiles, an aggregate client data instrument, a project overview instrument, and a staff time and budget instrument. Findings are summarized according to the following topics: clients served (age, living arrangement), strategies employed (negotiation vs. litigation), cost findings (demonstrating a large range of costs), and efficacy in bringing about broad-based changes in the service delivery systems. Six implications of the finding are highlighted, including that the relationships between mental health professionals and advocates do not have to be adversarial, that advocacy activities are not characteristically confrontational, and that legitimation of advocacy programs in state statutes and/or regulations may ensure their continued existence. (CL)

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EVALUATION OF ADVOCACY MODELS

By Valerie J. Bradley

I would like to describe an evaluation of 10 advocacy projects providing services to developmentally disabled and mentally ill persons around the country. Both the evaluation and portions of advocacy projects were funded by the Department of Health and Human Services. The study results are based on information gathered during the second and final year of a two year evaluation.

First, I would like to characterize the ten projects that comprised the evaluation. Two of the projects, the Client Advocacy Program in Wisconsin and the Patient Advocacy Office in California, fall into the category of internal rights protection organizations. Five of the projects, Vermont Mental Health Law Project, Idaho Mental Disability Law Unit, North Shore Children's Law Project, Denver Legal Center for Handicapped Citizens, and the New Jersey Division of Mental Health Advocacy, can be classified as independent legal advocacy mechanisms. One of the projects, Rubicon Independent Living Program, trains mentally disabled persons to advocate on their own behalf. The remaining two projects, Patients' Rights Advocacy Services of San Francisco and Mental Health Advocacy Project of Santa Clara County, provide legal and other advocacy services in partnership with local government.

The range of projects evaluated indicates that the study was more an assessment of discrete approaches to advocacy than an analysis of an interconnected network of advocacy programs. The

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projects studied also varied widely in terms of their auspices, the level of their resources, the target population served, staff training and qualifications, and scope of services.

The objectives of the evaluation study are as follows:

- To describe each of the ten advocacy projects in terms of:
  - * staffing;
  - * sociopolitical context;
  - * project history and current mission;
  - * clients served.
- To describe commonalities and differences across projects in terms of:
  - * goals;
  - * approaches or strategies;
  - * outcomes of advocacy activities; and
  - * costs.
- To establish a listing of commonly-valued goals of advocacy and to assess the extent to which project activities
  - * changed the delivery of services to mentally disabled clients;
  - * succeeded in promoting and implementing patients rights;
  - * and effected systemic change and reform.
- To document perceptions of the effectiveness of advocacy services among clients, direct service providers, administrators in institutions and state agencies, and others in the communities served by advocacy programs.

In order to ascertain what the goals were for each of the ten projects, the initial project activity involved a "goals negotiation" process. Evaluation staff worked with key staff in the advocacy agencies to elicit their four primary client-targeted

goals and their two most important system reform goals. These six goals formed the core of the evaluation for each of the ten advocacy projects.

Four instruments were used to collect information on a number of variables related to the six selected goals:

1. Individual Client Profile -- This instrument consisted of two sections. The first portion included information about individual client characteristics, problems presented, strategies used, and interim and final outcomes for the case. The second section recorded staff time spent on activities related to the case in six activity areas.

2. Aggregate Client Data Collection Instrument -- This tool was used to record information on all cases opened and closed by the project during each month, for all six months of the data collection period.

3. Project Overview Instrument -- This format recorded general information about project caseloads and requested information on system reform activities undertaken in the identified areas.

4. Staff Time and Budget Instrument -- This form collected detailed information on project resources and costs, including figures for income sources, staff salaries and overhead expenses. Staff also indicated the proportion of their time spent in each activity area.

Additionally, two to three day site visits were conducted at each agency. During the site visit, evaluation staff observed the advocates' routines, talked with clients, and interviewed relevant key informants at the state and local level including state mental health officials, judges, legislators, hospital administrators, generic service providers, residential proprietors, and other advocates.

SUMMARY OF FINDINGS

A. Quantitative Findings

With respect to the types of clients served by the ten advocacy projects, it is interesting to note that -- with the exception of one project -- very few children were served. Additionally, across projects, very few elderly individuals were served. Whether the concentration on non-elderly adults is random or by design is not clear. What may be more clear is that there is a need to explore the availability of specialized advocacy services for these two age groups.

With the exception of the Wisconsin, New Jersey, and Idaho projects, which concentrated almost exclusively on institutionalized clients, the remaining projects focused a significant portion of their energies on the problems of persons making the transition from an institutional to a community setting or attempting to maintain themselves in the community. This may suggest that the projects are targeting their services on clients who have traditionally "fallen through the cracks," including persons requiring assistance in making the community transition and community-based persons who are not part of any mental health support system. Additionally, projects have taken on so-called entitlement advocacy (e.g., securing Supplemental Security Income, housing, etc.) not always available from traditional mental health agencies.

Reviewing the data on strategies employed by advocacy projects, it is interesting to note that negotiation not litigation was the strategy of choice among the projects. The use of negotiation also resulted in the most favorable outcomes. This finding to

some extent dispels the notion that advocacy projects employ confrontational means to represent their clients to the exclusion of other techniques. In fact, virtually every project leaned heavily on negotiation as a means of resolving disputes.

B. Cost Findings

The costs of advocacy programs are difficult to find and compare since projects employ different accounting systems. Given the subjective elements involved, and because of the small number of programs and clients under study, the cost findings should be seen as descriptive.

We found that the size of advocacy programs varied markedly in terms of operating expenditures (from less than $50,000 to in excess of $1,500,000 annually), and that the relative amounts paid for staff salaries and wages, fringe benefits, and other non-personnel costs likewise vary considerably from program to program. The most expensive activities performed by advocates were administrative actions and investigation. Referral was predictably the least expensive service per case.

The cost of children's cases ran higher than adult cases, and among adult clients, the cost per case for persons with developmental disabilities was higher overall for most categories of service than the cost per case of persons who were mentally ill.

Advocacy project costs appear quite low. There are a number of factors that account for this phenomenon. Most of the legal services -- which are as a rule expensive -- are fairly routine and uncomplicated. In fact, most of the programs purposely avoided complicated cases in order to maximize their limited and

dwindling resourses. Moreover, the costs of the most expensive and complex activity, class action lawsuits, were spread across a number of clients. Finally, the personnel wage rates and non-personnel costs are especially low when compared to other legal and human service agencies.

C. Qualitative Findings

An assessment of the projects' efficacy in bringing about more broad based change in the service delivery system suggested the following:

- Over the two years of the evaluation, many of the projects were increasingly seen as resources to service providers in the interpretation and clarification of patients rights regulations.
- In states where significant successes had been obtained in Year 1, projects concentrated on institutionalizing or implementing past advocacy gains.
- Other projects worked to codify reforms in state statutes and, in some instances, advocacy staff were seen as a significant source of expertise in the areas of legislative drafting and constitutional law.
- Several projects used their access to information about entitlements and rights as a means of influencing providers and other advocates. Over time, these projects became seen as sources of technical assistance on key federal regulatory and statutory provisions.
- A few projects stressed self advocacy among clients and were successful in assisting clients to bring about change on their own behalf.

RECOMMENDATIONS AND REFLECTIONS

As I mentioned, the second year of the evaluation provided an opportunity to observe the provision of advocacy services during a period of rapidly declining resources. In fact, by the end of the study, two of the original ten projects were out

of business. Interestingly, with the exception of one project, those projects that had managed to develop a formal funding relationship with a state or local government -- or were part of state government -- remained. Specifically, the projects that ceased operations were Vermont Mental Health Law Project, and the Idaho Mental Disability Law Unit. The two were both funded primarily with Legal Services monies.

Of the projects still in operation, two are internal state advocacy projects (California and Wisconsin), one is an independent state-run advocacy project (New Jersey), and one is the state Protection and Advocacy agency (Denver Legal Center for Handicapped Citizens). Three other agencies -- Rubicon Independent Living Program, Santa Clara County Mental Health Advocacy Project, and San Francisco Patients Rights Advocacy Services -- all have contracts with the local county mental health department.

The following are some observations and suggestions:

1. The relationships between mental health professionals and advocates do not have to be adversarial in every instance. In fact, as funding becomes more scarce, the mental health system may have to rely more and more on the skills of advocates to protect the entitlements of mentally disabled persons.

2. Given the current fiscal realities and the pressures that they create on the provision of mental health and related services, there is a potential danger that advocacy agencies may be drawn into more case management-related activities thereby diverting energy and funds from core advocacy services.

3. Both years of the study suggest that advocacy activities are not characteristically confrontational, nor do they involve litigation as a rule. This study, however, suggests that the presence of a lawyer on the staff or in the network of the project enhances the project's effectiveness because potential for litigation is present.

4. Clearly, this evaluation has limitations and it represents a beginning attempt to develop a methodology for assessing the impact of advocacy services. Given the importance of client advocacy in the mental disabilities system, more should be done by way of research into the process and outcomes of a range of advocacy interventions.

5. Like mental health services, advocacy projects suffer from the fragmentation that multiple funding streams create. Thus, a single funding source for the support of advocacy services would result in the maximum stability and coherence for such services.

6. If advocacy programs are to persist, they should be legitimized in state statute and/or regulation.

There are many other implications that can be highlighted, but the general theme that emerges from this two year undertaking is that advocacy services can and should be a permanent facet of any comprehensive mental health system. As we have come to understand, persons with severe mental disabilities are often unable to cope with the complexities and irrationalities of living, and securing and maintaining the resources necessary to meet their basic needs. Advocates provide the signposts and road maps that make the day-to-day struggle somewhat easier.